

End Stage Kidney Disease and Quality of Life: An Overview

Waleed Al-Rajhi¹ and Issa Al Salmi^{2,3*}

¹College of Pharmacy and Nursing, Nizwa University, Oman

²The Renal Medicine, The Royal Hospital, Oman

³Medicine Department, Oman Medical Specialty Board, Oman

ARTICLE INFO

Received Date: January 20, 2022
Accepted Date: February 15, 2022
Published Date: February 18, 2022

KEYWORDS

End-stage kidney disease
Quality of life
Health related quality of life
Psychological factors
Socio-demographical factors

Copyright: © 2022 Issa Al Salmi. Journal Of Nephrology & Kidney Diseases. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Citation for this article: Issa Al Salmi. End Stage Kidney Disease and Quality of Life: An Overview. Journal Of Nephrology & Kidney Diseases. 2022; 4(1):125

Corresponding author:

Dr. Issa Al Salmi,
The Royal Hospital, 23 July Street, P O
Box 1331, code 111, Muscat, Oman,
Tel: 968 92709000; Fax: 968 245
99966; ORCID: 0000-0002-3443-
5972; Research ID: J-4622-2014;
Email: isa@ausdoctors.net

ABSTRACT

Introduction: End-Stage Kidney Disease (ESKD) is a serious, irreversible condition that affects a significant number of people worldwide. The interaction between symptom burden, physical, psychological and socio-demographical factors is important in understanding Health Related Quality of Life (HRQoL) in ESKD.

Method: This paper introduces the nature, severity and prevalence of ESKD, and its subsequent consequence on patients' lives. It discusses also the rationale for the study focus of QoL in this patient group, presents a list of definitions of the terms used in this study

Results: Most studies were conducted within Western culture, with only two found that examined QoL and HRQoL aspects in ESKD patients in the Middle East (ME) world. The results of these studies showed a low HRQoL among ME patients with ESKD, with a significant score variation evident within the different subdomains of HRQoL that were assessed.

Conclusion: Due to cultural and religious beliefs that may influence patients' perceptions about QoL, measuring QoL and HRQoL should be considered as an individualized concept.

The majority of studies that assessed QoL of patients with ESKD mainly focused on health related QoL, and no studies were found which comprehensively assessed biological function, symptoms, functional status, general health perceptions, and various characteristics of the individuals and their environment.

INTRODUCTION

End-Stage Kidney Disease (ESKD) is a serious, irreversible condition that affects a significant number of people worldwide [1]. ESKD occurs when the estimated Glomerular Filtration Rate (eGFR), is $<10-15$ ml/min/1.73m². An International cross sectional survey showed that median prevalence of kidney replacement therapy globally was 759 per million population (pmp), varying from 4 pmp in Rwanda to 3392 pmp in Taiwan [1]. These figures clearly show the incidence of ESKD is increasing substantially which, as a result, means the impact of the condition and its treatment has widespread consequences for healthcare services, individuals, and society [2-6].

Kidney dysfunction could result from any disease process affecting one or more parts of the kidney including blood vessels, the glomeruli, kidney tubules, and bladder or urethra. The commonest causes of ESKD are: 1) chronic glomerulopathy which is basically an alteration in the immune system in patients in which antibodies damage capillary membranes in the glomerulus; 2) diabetes mellitus could also affect blood vessels of the kidney causing narrowing by arteriosclerosis, 3) ischemic nephropathy which is manifested by ischemia in the kidney caused by hypertension and ageing; 4) hereditary kidney disease such polycystic kidney disease and Alport's Syndrome; and 5) obstructive uropathy.

Indeed, conditions such as diabetes and hypertension are dominant causes of ESKD in the ME including Gulf Cooperation Countries (GCC) [7,8]. Around 40% of patients with diabetes are prone to develop diabetic nephropathy, although it can take around 10 to 20 years between the first sign of kidney damage and need for dialysis [8].

ESKD causes significant biochemical abnormalities leading to symptom groups such as the uremic syndrome that may impact negatively on an individual's quality of life [9]. Usually the associated symptoms appear late when the renal function is less than 15 % of normal (DOQI Guidelines, 2014). The majority of patients present clinically very late where they require immediate dialysis at time of diagnosis to remove the accumulative waste product in their blood. Consequently, almost all body organs are affected by the accumulative waste product including the gastro-intestinal tract, central nervous system, cardiovascular system, musculo-skeletal system, hematological system, skin, and reproductive organs. Studies that measured the prevalence of symptoms in patients with ESKD reported that fatigue, pruritus, and pain were rated as the most distressing to ESKD patients. Fatigue, for instance, is consistently ranked as the highest debilitating symptom in HD patients [10], and pain has been identified as an independent predictor of HRQoL [11-14]. Pruritus was associated with the most intense symptoms and correlated negatively with all HRQoL domains [15-17].

The treatment of ESKD starts virtually when renal function deteriorates to more than 80% and kidneys become unable to remove waste products from blood (National Kidney Foundation Guideline, 2005). Although kidney transplantation

is considered the gold standard for patients with ESKD, practically it is not easy due to the fact that demand for kidneys exceeds the available supply. Instead, the best RRT option available for ESKD or what is clinically called Hemodialysis (HD). Hemodialysis usually commences when the remaining percentage of renal function is insufficient to excrete urea and other toxins from blood which usually leads to the emergence of severe symptoms. HD is the most common renal replacement therapy worldwide. It is performed by filtering patients' blood for three to five hours two to three times every week. Prior to commencing HD, patients are usually required to undergo a surgical procedure to create vascular access so that two needles can be connected to withdraw and return filtered blood. The main advantages of HD are its ability to amend the proportions of body fluids according to dialysis specifications, and efficient removal of body waste. Although HD is a safe procedure which can be performed in out-patients' clinics or patients' homes, complications may occur including hypotension, a sense of fatigue, and hardening of the arteries.

Treating ESKD and its related symptoms has significant costs, not only for the healthcare system but also for the individuals. In the UK, where ESKD represents only 0.05% of the total population, the estimated total cost to the National Health Service (NHS) of managing renal failure patients comprises approximately 2% of its total budget (Kidney Disease Key factors & Figures, 2016, NHS) [18,19]. In countries that do not have a national health system, patients with ESKD may be responsible for the cost of their own treatment and such costs might have a significant and enduring impact on the financial status of patients' families. The cost of caring for ESKD patients is likely to increase over time, and there are issues around long-term sustainability of these costs [2,3].

Given the characteristics of the each and every population in relation to culture, and religion, it is essential to use different measures including religious and spiritual measures in these population. The measures used in many studies were initially developed in western counties and had been translated into different languages including ME region.

Hence, the aim of this review is to identify the psychological factors, socio-demographical factors, and measures that are used in assessing QoL and HRQoL among end-stage kidney disease patients.

METHODS

A comprehensive search was made using several electronic literature databases accessed via the Library and Learning Centre website of the University of Dundee. The search was conducted in three phases: first, by accessing the topic-relevant internet database electronic literature databases [SCOPUS, Cochran Library, ProQuest (ASSIA) and EBSCO (CINAHL and Medline)]; second, secondary internet resources were consulted, such as ScienceDirect and PubMed; and finally, a retrograde search was made through citations from the articles already identified. EBSCO, which consists of CINAHL and Medline, was the initial database accessed as it is known to contain regularly updated evidence-based healthcare literature.

The literature search was not limited to any specific year of publication in order to screen most of the existing relevant evidence. English and translated articles from different languages were used in the search to include different populations in the review, thereby validating the generalisation of the results. The keywords used in the search were: (ESRD AND QoL OR ESRD AND HRQoL); ("QoL AND HRQoL AND predictors"); ("chronic kidney failure OR chronic renal failure AND QoL"); ("HRQoL AND QoL AND measurement"); (QoL AND HRQoL AND conceptualisation OR domains); ("QoL AND HRQoL AND ESRD AND operationalisation") AND haemodialysis.

RESULTS

Quality of Life, Health, and Health-related Quality of Life

The notion of quality of life (QoL) in nephrology started appearing in literature in the 1970s. The majority of these studies were conducted in the UK, Canada, USA, and Netherlands. Since then, numerous studies using different designs including quantitative and qualitative approaches have been conducted. Quantitative studies in particular have used different tools and measures to examine QoL. Similarly, these studies have used several clinical and sociodemographic variables to examine QoL among ESKD patients. Reviewing the published studies that have examined QoL in this group of patients has helped in identifying the gap that exists in current literature and should inform this study design. There are very few studies that have used a combination of an individualized

QoL instrument, disease specific measure, HRQoL measure, and symptoms-specific measures.

QoL is a complex and scattered concept that makes a significant impact on research exploring patient experience and practice. It is often used to describe different physical and psychosocial variables [20] including health status, functions, behaviors, life satisfaction, perceptions, and symptoms [21,22]. In contemporary health care research, the term QoL has been linked and used interchangeably with different related concepts such as HRQoL and functional ability. The interchangeable use of the term's 'health', 'functional ability' and 'QoL', far from clarifying and providing exact meaning, might add additional confusion. Despite inconsistency and the complexity of defining QoL, there is a consistency in literature that QoL is a multidimensional concept [23-25]. Due to cultural and religious beliefs that may influence patients' perceptions about QoL, measuring QoL should be considered as an individualized concept [26-29].

The relationship between QoL and Health

There is an increased acceptance in the literature of using QoL as a critical endpoint in medical research. Yet, there is little consensus on how it differs from perceived health-status. The term 'health' is usually referred to as the absence of disease and illness, which might indicate a good level of quality of life on an individual level. Most of the measures of health status have considered health as a baseline for QoL [30,31]. However, a positive conception of health is difficult to measure due to the lack of agreement over its definition [32]. Also, it is difficult to determine if the state of health has been achieved because of the absence of a unified operational definition for the term 'health'. Clinicians' judgment might focus on the absence of disease, whereas others professionals, and indeed patients, might see it as the ability to carry out normal everyday tasks, feeling strong and fit to carry out life.

The WHO definition of 'health' as a state of complete physical, mental and social well-being provided a new focus to the borders of the meaning of health rather than a narrow (disease-based) focus [33]. This step was followed by the development of measures of positive health. Currently, there is broad agreement that the concept of positive health is more than the absence of disease or even disability, but is about full functioning, efficiency of mind and body and social adjustment.

By reflecting on the concept of QoL, it can be realized that 'health' is a component of QoL with a kind of tautology and overlap existing between the concepts.

Health-related QoL

Because the majority of life domains are related to health, the term health-related quality of life 'HRQoL' is used to differentiate and specify health related issues from the general issues of quality of life. The term HRQoL was developed by psychological and sociological researchers primarily to help measure the health domains that influence an individual's physical and mental health status [34]. HRQoL as a concept, therefore, is more appropriate in that it can be measured within distinct components which can be interpreted separately [35-37].

Both QoL and HRQoL concepts represent patients' own satisfaction with life and can be influenced by how they perceive the physical, mental, and social effects of ESKD on their daily living [36,38]. This suggests that QoL and HRQoL are individualized concepts [39,40]. That is, ESKD may be considered as an irritation for one patient but may be severely frustrating for others [41]. Studies that examined QoL and HRQoL in ESKD patients with different ethnicities and religious beliefs found significant differences in their perceptions about factors that make up their overall QoL [26,27,42]. Assessing QoL and HRQoL, therefore, using measures that are able to capture patients' individualized experiences of health becomes a vital and often required part of health outcomes appraisal [10,43, 44].

Measurement of HRQoL has the potential to provide important additional information about the wellbeing of individuals with ESKD which is not readily available from the clinical and laboratory assessments currently used to monitor patients [45]. Various measures are used with different languages to assess HRQoL and its predictors, such as generic and disease-specific instruments. Generic measures are the ones most commonly used to evaluate different aspects of HRQoL: physical, psychological and social as well as perceived well-being; and disease or condition-specific measures which evaluate the particular symptom or condition that might be associated with level of QoL. Measuring such personal and complex theoretical

concepts, therefore, is difficult, and, as a result, individualized QoL tools were developed. These tools allow respondents to nominate the areas of life which are most important, rate their level of functioning or satisfaction with each, and indicate the relative importance of each to their overall quality of life. However, there are very limited studies that have used a combination of generic QoL measures, disease-specific measures, and QoL individualized measures.

HRQoL and dialysis patients

The studies that examined HRQoL among ESKD patients revealed that their HRQoL is affected due to major physical, mental, and socioeconomic factors. Patients affected by ESKD have to receive dialysis for survival on a routine basis which creates uncertainty about their future, which may change their perception about their self and self-confidence, and sometimes bring about a reversal in family roles [46,47].

Functional status, including physical functioning, role functioning, social functioning, and mental functioning as a result of disease symptoms and treatment regimens, is usually limited in patients with ESKD. Studies that have used physical performance, health, and self-reported measures reported low physical functioning in patients with ESKD [48-50]. Patients engaged in social activities reported better HRQoL, whereas social isolation and decreased social interactions were associated with worse HRQoL [51]. This might suggest that patients who develop an appropriate adaptive strategy to manage the stress stemming from the disease and subsequent HD treatment might be able to maintain a better QoL [52-56].

Co-morbidities such as malnutrition, anemia, and Congestive Heart Failure (CHF) are strongly associated with HRQoL in individuals with ESKD. Hypoalbuminemia (albumin <35g/L) influenced physical composite summary negatively by affecting physical functioning and general health and emotional well-being [57]. Anemia has also been shown to impact on HRQoL in persons with ESKD. Anemia severity (hematocrit <33%) is associated with poor physical function, whereas the effect on social function was modest [58,59]. A pre-existing myocardial infarction was the most common observed predictor of decline in HRQoL influencing physical role-functioning, general health and emotional role functioning. Similarly, a history of Congestive Heart Failure (CHF) was associated with decline of HRQoL in ESKD patients [60-62].

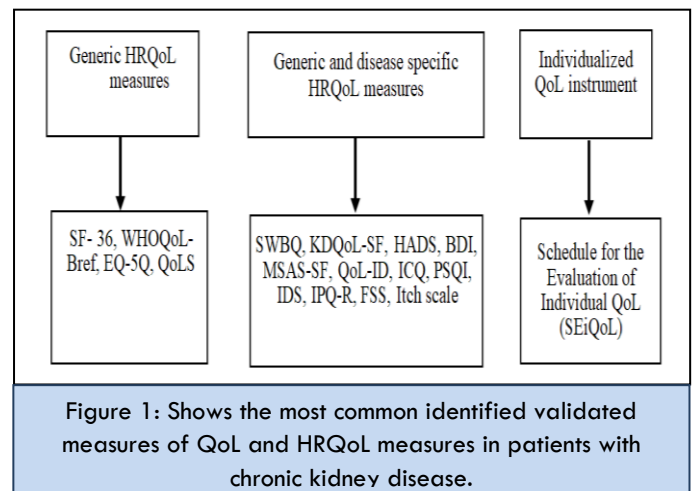
Demographic factors, such as gender, age, socioeconomic status, and marital status, correlate with HRQoL in ESKD patients. Female patients on HD consistently reported worse HRQoL when compared to men [62,63]. They had lower scores for physical functioning, emotional well-being, social function, and increased fatigue. Elderly patients also reported lower HRQoL in most of the HRQoL measures, particularly on physical functioning. Employment and marital status were associated positively with score of QoL and HRQoL [64-66]. Patients who were employed and were married or had a marriage-like relationship had higher mental health [64-66]. Similarly, patients who had a higher level of education associated with better HRQoL [67].

Healthcare providers including nephrologists and nephrology nurses are encouraged to deal with patients from various ethnicities and cultures and promote the teaching of culturally safe practice and meeting an individual's needs for health care services on an equality basis [68]. Nephrologists and nephrology nurses are the center of care for ESKD patients; thus, they should utilize cross cultural knowledge and culturally sensitive skills in providing and maximizing good patient care outcomes. ESKD patients are close to the nephrology healthcare team because they spend around 15 hours each week in dialysis units attending dialysis session. Thus, the healthcare providers need to understand that HRQoL is important in improving renal care services. Nephrology nurses should focus on the development and application of clear concepts that that look into psychosocial aspects of care, like emotional status, and social involvement.

Measures used to assess QoL and HRQoL among ESKD patients

Several measures are used in assessing QoL and HRQoL with an interchangeable use of terms across literature. The most common identified validated measures of QoL and HRQoL measures in patients with CKD can be categorized as shown in Figure 1: 1) a generic measure to capture aspects related to overall quality of life; 2) a kidney disease-specific measure to assess aspects related entirely to the ESKD patients which would also gather the clinical-related factors; and 3) an individualised QoL measure to be used to explore how ESKD patients perceive the meaning of QoL. Most of the measures used to assess QoL and HRQoL were proven relevant

according to the reported psychometric-quality results. Most of the researchers acknowledged that there were difficulties in determining whether the measures used measured QoL exactly. This is possibly due to the absence of a consensus or gold standard for the meaning of QoL. It is indeed a challenge to determine whether any measures of QoL and HRQoL tap into the intended aspect of any one individual's experience [69]. There is also the possibility of variation between the standardised QoL measures and the patient perceived QoL instrument, which adds a further limitation to the measurement of QoL. Possible reasons for this potential disconnect might be cultural differences, coping mechanisms and patient values. Using a more individualised measure of QoL would perhaps allow and advise patients to select areas of their life that they view as being most relevant to their own well-being [70].



(SF-36v2): Short Form36 version 2; (WHOQoL-Bref): World Health Organisation Quality of Life-Bref; (EQ)- 5D: EuroQol; (QoLS): Quality of Life Scale; (KDQoL-SF): Kidney Disease Quality of Life-Short Form; (HADS): Anxiety and Depression Scale; (ESRD-SI): End Stage Renal Disease Severity Index; (IPQ): Illness Perceptions Questionnaire; (MSAS-SF): Memorial Symptom Assessment Scale Short Form; (QoL-ID): Ferrans and Powers Quality of Life Index-Dialysis; (ICQ): Illness Cognition Questionnaire; (PSQI): Pittsburgh Sleep Quality Index; (IDS): Fatigue Severity Scale (FSS) Index of Disease Severity; (IPQ-R): Revised Illness Perception Questionnaire.

Likewise, selecting a measure of QoL can be difficult because of the extensiveness of the concept of QoL. The measure should provide an inclusive view of most of the life aspects that might influence QoL in patients affected by ESKD. The disease-specific measures are helpful for researchers as they provide a better focus on functional areas of a particular concern [71]. Although instruments that measure a specific condition/symptom or disease appear attractive for use in clinical practice and research as a screening instrument to identify a symptom's severity, they are limited in their scope for measuring broader areas of life aspects [72]. Using a generic measure could provide a broader view on the overall aspects associated with QoL. But again, this is unlikely to show the real benefits of specific interventions which demand a use of disease-specific measures. To overcome this, there should be a balance in capturing the aspects, based entirely on the patient's own perceptions, impacted upon by the disease in a patient's life and in his or her overall aspects of life.

In spite of the fact that the majority of studies that examine QoL and HRQoL have been conducted within a Western culture, a limited number of studies are available examining QoL and HRQoL aspects in the Arab world. These studies showed a low HRQoL among Arab patients affected by ESRD, with a significant score variation evident within the different subdomains of HRQoL that were assessed [73,74]. A possible reason for this variation could be the specificities of each country in terms of social and cultural life, economic status and level of healthcare services. Thus, the determinants and influencing factors of QoL and HRQoL are likely to differ among patients within different countries [75]. Thus, great consideration is needed when determining the most appropriate measures that will capture the different aspects of QoL within any society context, including Arab world.

Justification and study relevance to clinical and policy change

The interaction between symptom burden, physical, psychological and socio-demographical factors is important in understanding HRQoL in ESKD. Most studies that assessed QoL of patients with ESKD mainly focused on health related QoL, and no studies were found which comprehensively assessed biological function, symptoms, functional status, general health perceptions, and various characteristics of the individuals and

their environment. Even with studies that used more than one measure of QoL, the researchers did not articulate a holistic conceptual framework to guide their study, thus limiting the independent variables used to explain QoL.

In addition, most studies were conducted within Western culture, with only two found that examined QoL and HRQoL aspects in ESKD patients in the Arab world. The results of these studies showed a low HRQoL among ME patients with ESKD, with a significant score variation evident within the different subdomains of HRQoL that were assessed. As in many other Asian countries, no studies were found that had been conducted in ME to assess QoL in this group of patients, or on how these patients perceived their QoL. As a result, there is a need to fill these gaps and to plan future studies.

The results of such a study in our region can create an evidence base upon which future health care services can be developed within the nephrology care services in GCC. Identifying the factors that impact the level of QoL and HRQoL in this group of the population can help to design new strategies to improve their HRQoL in relation to clinical factors, psychological issues, physical functioning, social support, symptom burden, and spiritual factors. It can, also, promote the use of HRQoL measures in clinical practice to monitor the patients' condition and associated symptoms such as fatigue and pain. Also, this will enable us to provide certain management strategies that may suit all, or at least most, people worldwide. A randomized single-blind clinical trial, by Cimen et al, found that music therapy can be a complimentary treatment for patients undergoing fistula surgery [76]. It can reduce anxiety and perceived pain, improve intraoperative hemodynamic parameters and enhance treatment satisfaction, thus may contribute to better compliance of the patients. This may improve QoL among our patients during their various management strategies.

Validating the HRQoL measures in an GCC population will benefit clinical practice as it is likely to provide clinicians with specific validated tools to assess their patients which can greatly improve the integration of HRQoL data into clinical practice. A major benefit to integrating these measures into routine clinical practice is the potential for identifying symptoms and problems that may result in improved patient care and clinical outcomes over time. Such study will significantly

contribute to the knowledge of understanding the issues around HRQoL among cultures. It will influence the nephrology services in GCC and help clinicians in developing intervention plans based on a holistic view of physical and psychosocial views. It is also anticipated to facilitate the understanding of the renal failure patients' perceptions about their disease, which can be then tailored into their intervention plans.

Assessing the perceptions of this patient group in GCC, using multi measures including an individualized QoL measure, would help to identify their predictors and measures so that they can be tackled to improve patients' HRQoL; and support the shift of healthcare services from episodic treatment to a treatment that meets their ongoing needs.

A number of assumptions underlie the methods that may be used in QoL study. First, the concept of QoL is a multidimensional construct. Second, the abstracts and concepts that are unobservable, for instance, symptom burden and health perception, can be assessed by specific-related measures and statistical analysis. This assumption addresses the belief that patients with ESKD will respond to study measures that assess symptom burden, functional status, general health perception, QoL, and individual and environmental characteristics in accurate and honest answers. Lastly, obtained clinical and medical data may better reflect the reality of our patients.

CONCLUSION

An intervention model based on QoL will be of paramount importance to the hierarchy making healthcare decisions, relevant stakeholders, and those providing nephrology services. This needs to be in line with the aim of the long-term healthcare plan that emphasizes that quality of health as one of its target priorities. The healthcare providers need to understand that HRQoL is important in improving renal care services. In many countries, nephrology care still needs to focus on the development and application of clear concepts that look into psychosocial aspects of care, like emotional status, and social involvement. In addition, various stakeholders such as the American Society of Nephrology probably need to address this issue regularly in its meetings that are being attended by thousands of individuals who provides nephrology to huge number of patients worldwide.

DISCLOSURE OF POTENTIAL CONFLICTS OF INTEREST

The study required no approved by the Scientific Research Committee at the Royal Hospital, Muscat, Oman.

CONSENT FOR PUBLICATION

All authors have agreed to the publication and to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

AUTHOR CONTRIBUTION STATEMENT

All authors have contributed equally

DATA AVAILABILITY STATEMENT

No data provided for this study.

INFORMED CONSENT

No consent required for this study.

FUNDING

No funding available.

CONFLICT OF INTEREST

Authors declare no conflict of interest

ACKNOWLEDGMENT

We would like to thank all our patients and staff for their trust on us.

REFERENCES

1. Bello AK, Levin A, Lunney M, Osman MA, Ye F, et al. (2019). Status of care for end stage kidney disease in countries and regions worldwide: international cross sectional survey. *BMJ*. 367: 15873.
2. Al Ismaili F, Al Salmi I, Al Maimani Y, Metry AM, Al Marhoobi H, et al. (2017). Epidemiological Transition of End-Stage Kidney Disease in Oman. *Kidney Int Rep*. 2: 27-35.
3. Al Alawi I, Al Salmi I, Al Mawali A, Al Maimani Y, Sayer JA. (2017). End-Stage Kidney Failure in Oman: An Analysis of Registry Data with an Emphasis on Congenital and Inherited Renal Diseases. *Int J Nephrol*. 2017: 6403985.
4. Al Alawi IH, Al Salmi I, Al Mawali A, Sayer JA. (2017). Kidney Disease in Oman: a View of the Current and Future Landscapes. *Iran J Kidney Dis*. 11: 263-270.
5. Al Majarfi A, Al Salmi I, Metry A, Al Ismaili F, Hola A, et al. (2018). Epidemiology of Patients at Initial Treatment with Hemodialysis. *ARC Journal of Nephrology*. 3: 6-12.

6. Metry AM, Al Salmi I, Al Balushi F, Yousef MA, Al Ismaili F, et al. (2019). Systemic Lupus Erythematosus: Symptoms and Signs at Initial Presentations. *Antiinflamm Antiallergy Agents Med Chem.* 18: 142-150.
7. AlSahow A, AlRukhaimi M, Al Wakeel J, Al-Ghamdi SM, AlGhareeb S, et al. (2016). Demographics and key clinical characteristics of hemodialysis patients from the Gulf Cooperation Council countries enrolled in the dialysis outcomes and practice patterns study phase 5 (2012-2015). *Saudi J Kidney Dis Transpl.* 27: S12-23.
8. Hassanien AA, Al-Shaikh F, Vamos EP, Yadegarfar G, Majeed A. (2012). Epidemiology of end-stage renal disease in the countries of the Gulf Cooperation Council: a systematic review. *JRSM Short Rep.* 3: 38.
9. Trivedi DD. (2011). Palliative dialysis in end-stage renal disease. *Am J Hosp Palliat Care.* 28: 539-542.
10. Jablonski A. (2007). The multidimensional characteristics of symptoms reported by patients on hemodialysis. *Nephrol Nurs J.* 34: 29-37.
11. Fukuhara S, Lopes AA, Bragg-Gresham JL, Kurokawa K, Mapes DL, et al. (2003). Health-related quality of life among dialysis patients on three continents: the Dialysis Outcomes and Practice Patterns Study. *Kidney Int.* 64: 1903-1910.
12. Lowney AC, Myles HT, Bristowe K, Lowney EL, Shepherd K, et al. (2015). Understanding What Influences the Health-Related Quality of Life of Hemodialysis Patients: A Collaborative Study in England and Ireland. *J Pain Symptom Manage.* 50: 778-85.
13. Painter P, Krasnoff JB, Kuskowski M, Frassetto L, Johansen K. (2012). Effects of modality change on health-related quality of life. *Hemodial Int.* 16: 377-386.
14. Santoro D, Satta E, Messina S, Costantino G, Savica V, et al. (2013). Pain in end-stage renal disease: a frequent and neglected clinical problem. *Clin Nephrol.* 79: S2-11.
15. Mettang T, Kremer AE. (2015). Uremic pruritus. *Kidney Int.* 87: 685-691.
16. Panuccio V, Tripepi R, Bellantoni M, Saporito L, Quattrone S, et al. (2017). Pruritus and quality of life in renal transplant patients. *Clin Transplant.* 3: 31.
17. Rehman IU, Chohan TA, Bukhsh A, Khan TM. (2019). Impact of Pruritus on Sleep Quality of Hemodialysis Patients: A Systematic Review and Meta-Analysis. *Medicina (Kaunas).* 55: 669.
18. Lamb EJ. (2008). United Kingdom guidelines for chronic kidney disease. *Scand J Clin Lab Invest Suppl.* 241: 16-22.
19. Roberts CJ, Farrow SC, Charny MC. (1985). How much can the NHS afford to spend to save a life or avoid a severe disability? *Lancet.* 1: 89-91.
20. Cameron A, Palm K, Follette V. (2010). Reaction to stressful life events: what predicts symptom severity? *J Anxiety Disord.* 24: 645-649.
21. Finkelstein FO, Arsenault KL, Taveras A, Awuah K, Finkelstein SH. (2012). Assessing and improving the health-related quality of life of patients with ESRD. *Nat Rev Nephrol.* 8: 718-724.
22. Finkelstein FO, Finkelstein SH. (2010). Reassessment of the care of the patient with chronic kidney disease. *Kidney Int.* 77: 945-947.
23. Bowling A, Hankins M, Windle G, Bilotta C, Grant R. (2013). A short measure of quality of life in older age: the performance of the brief Older People's Quality of Life questionnaire (OPQOL-brief). *Arch Gerontol Geriatr.* 56: 181-187.
24. Bowling A, Seetai S, Morris R, Ebrahim S. (2007). Quality of life among older people with poor functioning. The influence of perceived control over life. *Age Ageing.* 36: 310-315.
25. Bowling CB, Zhang R, Franch H, Huang Y, Mirk A, et al. (2015). Underreporting of nursing home utilization on the CMS-2728 in older incident dialysis patients and implications for assessing mortality risk. *BMC Nephrol.* 16: 32.
26. Ko B, Khurana A, Spencer J, Scott B, Hahn M, et al. (2007). Religious beliefs and quality of life in an American inner-city haemodialysis population. *Nephrol Dial Transplant.* 22: 2985-2990.
27. Patel SS, Shah VS, Peterson RA, Kimmel PL. (2002). Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. *Am J Kidney Dis.* 40: 1013-1022.
28. Ramirez SP, Macedo DS, Sales PM, Figueiredo SM, Daher EF, et al. (2012). The relationship between religious

- coping, psychological distress and quality of life in hemodialysis patients. *J Psychosom Res.* 72: 129-135.
29. Santos PR, Capote Junior J, Cavalcante Filho JRM, Ferreira TP, Dos Santos Filho JNG, et al. (2017). Religious coping methods predict depression and quality of life among end-stage renal disease patients undergoing hemodialysis: a cross-sectional study. *BMC Nephrol.* 18: 197.
 30. Hall T, Krahn GL, Horner-Johnson W, Lamb G, Rehabilitation R, et al. (2011). Examining functional content in widely used Health-Related Quality of Life scales. *Rehabil Psychol.* 56: 94-99.
 31. Jassal SV, Karaboyas A, Comment LA, Bieber BA, Morgenstern H, et al. (2016). Functional Dependence and Mortality in the International Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis.* 67: 283-292.
 32. Kurpas D, Church J, Mroczek B, Hans-Wytrychowska A, Nitsch-Osuch A, et al. (2013). The quality of primary health care for chronically ill patients: a cross-sectional study. *Adv Clin Exp Med.* 22: 501-511.
 33. Olsen JA, Misajon R. (2020). A conceptual map of health-related quality of life dimensions: key lessons for a new instrument. *Qual Life Res.* 29: 733-743.
 34. Cella D, Riley W, Stone A, Rothrock N, Reeve B, et al. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol.* 63: 1179-1194.
 35. Broers NJH, Martens RJH, Canaud B, Cornelis T, Dejagere T, et al. (2018). Health-related quality of life in end-stage renal disease patients: the effects of starting dialysis in the first year after the transition period. *Int Urol Nephrol.* 50: 1131-1142.
 36. Kraus MA, Fluck RJ, Weinhandl ED, Kansal S, Copland M, et al. (2016). Intensive Hemodialysis and Health-Related Quality of Life. *Am J Kidney Dis.* 68: S33-S42.
 37. Turkmen K, Yazici R, Solak Y, Guney I, Altintepe L, et al. (2012). Health-related quality of life, sleep quality, and depression in peritoneal dialysis and hemodialysis patients. *Hemodial Int.* 16: 198-206.
 38. Moura A, Madureira J, Alija P, Fernandes JC, Oliveira JG, et al. (2015). Predictors of health-related quality of life perceived by end-stage renal disease patients under online hemodiafiltration. *Qual Life Res.* 24: 1327-35.
 39. Griva K, Kang AW, Yu ZL, Mooppil NK, Foo M, et al. (2014). Quality of life and emotional distress between patients on peritoneal dialysis versus community-based hemodialysis. *Qual Life Res.* 23: 57-66.
 40. Griva K, Mooppil N, Seet P, Krishnan DS, James H, et al. (2011). The NKF-NUS hemodialysis trial protocol - a randomized controlled trial to determine the effectiveness of a self management intervention for hemodialysis patients. *BMC Nephrol.* 12: 4.
 41. Ferrans CE. (1996). Development of a conceptual model of quality of life. *Sch Inq Nurs Pract.* 10: 293-304.
 42. Fradelos EC, Tsaras K, Tzavella F, Koukia E, Papathanasiou IV, et al. (2017). Clinical, Social and Demographics Factors Associated with Spiritual Wellbeing in End Stage Renal Disease. *Adv Exp Med Biol.* 987: 77-88.
 43. Grubbs V, Tuot DS, Powe NR, O'Donoghue D, Chesla CA. (2017). System-Level Barriers and Facilitators for Foregoing or Withdrawing Dialysis: A Qualitative Study of Nephrologists in the United States and England. *Am J Kidney Dis.* 70: 602-610.
 44. Tucker CA, Cieza A, Riley AW, Stucki G, Lai JS, et al. (2014). Concept analysis of the patient reported outcomes measurement information system (PROMIS[®]) and the international classification of functioning, disability and health (ICF). *Qual Life Res.* 23: 1677-1686.
 45. Homaie Rad E, Mostafavi H, Delavari S, Mostafavi S. (2015). Health-related Quality of Life in Patients on Hemodialysis and Peritoneal Dialysis: a Meta-Analysis of Iranian Studies. *Iran J Kidney Dis.* 9: 386-393.
 46. Polaschek N. (2003). The experience of living on dialysis: a literature review. *Nephrol Nurs J.* 30: 303-309, 313.
 47. Salter ML, Kumar K, Law AH, Gupta N, Marks K, et al. (2015). Perceptions about hemodialysis and transplantation among African American adults with end-stage renal disease: inferences from focus groups. *BMC Nephrol.* 16: 49.
 48. Painter P. (2005). Physical functioning in end-stage renal disease patients: update 2005. *Hemodial Int.* 9: 218-235.
 49. Stefanovic V, Milojkovic M. (2005). Effects of physical exercise in patients with end stage renal failure, on

- dialysis and renal transplantation: current status and recommendations. *Int J Artif Organs*. 28: 8-15.
50. Wang AY, Sherrington C, Toyama T, Gallagher MP, Cass A, et al. (2017). Muscle strength, mobility, quality of life and falls in patients on maintenance haemodialysis: A prospective study. *Nephrology (Carlton)*. 22: 220-227.
 51. Walker RC, Hanson CS, Palmer SC, Howard K, Morton RL, et al. (2015). Patient and caregiver perspectives on home hemodialysis: a systematic review. *Am J Kidney Dis*. 65: 451-463.
 52. Cukor D, Coplan J, Brown C, Friedman S, Newville H, et al. (2008). Anxiety disorders in adults treated by hemodialysis: a single-center study. *Am J Kidney Dis*. 52: 128-136.
 53. Davison SN, Jhangri GS, Johnson JA. (2006). Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in haemodialysis patients. *Nephrol Dial Transplant*. 21: 3189-3195.
 54. Franke GH, Reimer J, Philipp T, Heemann U. (2003). Aspects of quality of life through end-stage renal disease. *Qual Life Res*. 12: 103-115.
 55. Prihodova L, Nagyova I, Rosenberger J, Roland R, Majernikova M, et al. (2015). Social participation after kidney transplantation as a predictor of graft loss and mortality over 10 years: a longitudinal study. *Transplantation*. 99: 568-575.
 56. Rocha Augusto C, Krzesinski JM, Warling X, Smelten N, Etienne AM. (2011). [The role of psychological interventions in dialysis: an exploratory study]. *Nephrol Ther*. 7: 211-218.
 57. Walters BA, Hays RD, Spritzer KL, Fridman M, Carter WB. (2002). Health-related quality of life, depressive symptoms, anemia, and malnutrition at hemodialysis initiation. *Am J Kidney Dis*. 40: 1185-1194.
 58. Emami Naini A, Moradi M, Mortazavi M, Amini Harandi A, Hadizadeh M, et al. (2012). Effects of Oral L-Carnitine Supplementation on Lipid Profile, Anemia, and Quality of Life in Chronic Renal Disease Patients under Hemodialysis: A Randomized, Double-Blinded, Placebo-Controlled Trial. *J Nutr Metab*. 2012: 510483.
 59. Furuland H, Linde T, Ahlmen J, Christensson A, Strombom U, et al. (2003). A randomized controlled trial of haemoglobin normalization with epoetin alfa in pre-dialysis and dialysis patients. *Nephrol Dial Transplant*. 18: 353-361.
 60. Silverberg D, Wexler D, Blum M, Schwartz D, Iaina A. (2004). The association between congestive heart failure and chronic renal disease. *Curr Opin Nephrol Hypertens*. 13: 163-170.
 61. Finkelstein FO, Wuerth D, Finkelstein SH. (2010). An approach to addressing depression in patients with chronic kidney disease. *Blood Purif*. 29: 121-124.
 62. Mujais SK, Story K, Brouillette J, Takano T, Soroka S, et al. (2009). Health-related quality of life in CKD Patients: correlates and evolution over time. *Clin J Am Soc Nephrol*. 4: 1293-301.
 63. Kontodimopoulos N, Pappa E, Niakas D. (2009). Gender- and age-related benefit of renal replacement therapy on health-related quality of life. *Scand J Caring Sci*. 23: 721-729.
 64. Hamilton AJ, Caskey FJ, Casula A, Ben-Shlomo Y, Inward CD. (2019). Psychosocial Health and Lifestyle Behaviors in Young Adults Receiving Renal Replacement Therapy Compared to the General Population: Findings From the SPEAK Study. *Am J Kidney Dis*. 73: 194-205.
 65. Tannor EK, Archer E, Kapembwa K, van Schalkwyk SC, Davids MR. (2017). Quality of life in patients on chronic dialysis in South Africa: a comparative mixed methods study. *BMC Nephrol*. 18: 4.
 66. Wicks MN, Milstead EJ, Hathaway DK, Cetingok M. (1997). Subjective burden and quality of life in family caregivers of patients with end stage renal disease. *ANNA J*. 24: 527-528, 31-8; discussion 39-40.
 67. Mapes DL, Bragg-Gresham JL, Bommer J, Fukuhara S, McKeivitt P, et al. (2004). Health-related quality of life in the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis*. 44: 54-60.
 68. Al Mawali AHN, Al Qasmi AM, Al Sabahi SMS, Idikula J, Elaty MAA, et al. (2017). Oman Vision 2050 for Health Research: A Strategic Plan for the Future Based on the Past and Present Experience. *Oman Med J*. 32: 86-96.
 69. Lee CP, Chertow GM, Zenios SA. (2009). An empiric estimate of the value of life: updating the renal dialysis cost-effectiveness standard. *Value Health*. 12: 80-87.

70. Ferri CV, Pruchno RA. (2009). Quality of life in end-stage renal disease patients: differences in patient and spouse perceptions. *Aging Ment Health*. 13: 706-714.
71. Glover C, Banks P, Carson A, Martin CR, Duffy T. (2011). Understanding and assessing the impact of end-stage renal disease on quality of life: a systematic review of the content validity of self-administered instruments used to assess health-related quality of life in end-stage renal disease. *Patient*. 4: 19-30.
72. Fryback DG, Palta M, Cherepanov D, Bolt D, Kim JS. (2010). Comparison of 5 health-related quality-of-life indexes using item response theory analysis. *Med Decis Making*. 30: 5-15.
73. Abd ElHafeez S, Sallam SA, Gad ZM, Zoccali C, Torino C, et al. (2012). Cultural adaptation and validation of the "Kidney Disease and Quality of Life--Short Form (KDQOL-SF™) version 1.3" questionnaire in Egypt. *BMC nephrology*. 13: 170.
74. A AL-J, Al-Onazi K, Binsalih S, Hejaili F, Al-Sayyari A. (2011). A study of quality of life and its determinants among hemodialysis patients using the KDQOL-SF instrument in one center in Saudi Arabia. *Arab J Nephrol Transplant*. 4: 125-130.
75. Bergland A, Narum I.(2007). Quality of Life: Diversity in Content and Meaning. 19: 115-139.
76. Cimen SG, Oğuz E, Gundogmus AG, Cimen S, Sandikci F, et al. (2020). Listening to music during arteriovenous fistula surgery alleviates anxiety: A randomized single-blind clinical trial. *World J Transplant*. 10: 79-89.